

Engaging & Empowering Communities by Building Capacity to Address HIV/AIDS and STDs



How 10 organizations addressed HIV/AIDS and STDs

Introduction

Until a vaccine is available to prevent HIV/AIDS, enhanced access to prevention and treatment services is the only option to slow down incidence of the disease. Community-based organizations are best positioned to engage and reduce discrimination and the stigma associated with people living with HIV/AIDS. They provide prevention or education programs that ensure access to services and treatments. Today, a diagnosis is no longer the death sentence it once was. The risk of HIV transmission has significantly reduced over the last three decades as a result of advances in HIV therapy and education; however, gains made could easily be reversed if we are complacent. The observed link between HIV, STDs, and the opioid epidemic has increased the risk of HIV outbreak. National data from the Centers for Disease Control and Prevention (CDC) indicate a rise in chlamydia, gonorrhea, and syphilis for the first time since 2006.¹ Recent data shows the interconnections between the opioid epidemic, HIV, hepatitis C (HCV), and other infectious diseases being spread by injection drug use.^{2,3} This is fast becoming a serious public health issue that weighs heavily on communities and service providers across both rural and urban communities in the United States.

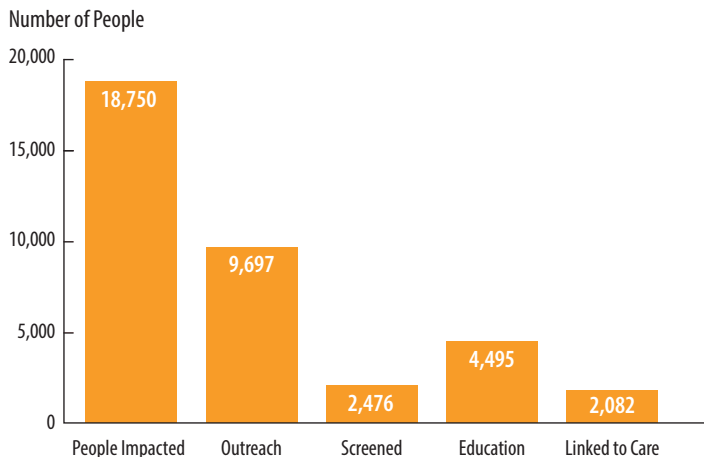
This white paper is the result of successful efforts of the Highmark Foundation (Foundation) in assisting 10 organizations with building capacity to improve access to HIV/AIDS and STD prevention programs and services with mini-grants totaling \$90,000. **Table 1** and **Figure 1** respectively show organizations by funding category, amount awarded, and geographic region.

Table 1 Organizations and Number of Participants by Category

Organization	Country	Number Participated in Outreach Events	Number Linked to Care	Number Screened for HIV/HCV & STDs	Number Prevention/Education	Totals
Ensuring Access to Services and Treatment						
AIDS Resource Alliance	Lycoming	0	4	0	0	4
Caritas House	Marion, Preston, and Monongalia (WV)	0	0	350	350	700
Co-County Wellness Services	Berks	5,100	1,800	418	2,398	9,716
Community Human Services	Allegheny	0	12	0	389	401
Milan Puskar Health Right	Monongalia (WV)	0	40	389	0	429
Pittsburgh AIDS Task Force	Allegheny	0	106	0	0	106
Planned Parenthood Keystone	Central PA (serves 38 counties)	1,800	0	99	99	1,998
SUBTOTAL		6,900	1,962	1,256	3,236	13,354
Providing Prevention/Education Programs						
Allentown Health Bureau	Lehigh	0	76	433	433	942
Central Outreach Resource and Referral Center	Allegheny	2,630	0	787	787	4,204
SUBTOTAL		2,630	76	1,220	1,220	5,146
Reducing Stigma and Discrimination						
Macedonia Family and Community Enrichment Center	Allegheny	167	44	0	39	250
SUBTOTAL		167	44	0	39	250
TOTALS		9,697	2,082	2,476	4,495	18,750

Table 1 and **Figure 1** illustrate organizations' successful delivery of treatment and educating people living with HIV/AIDS, including those at risk of infection. The information offers a breakdown of outreach participation, treatment, services, and prevention education provided by organization.

Figure 1
Participants Served by Highmark Foundation Grant



A total of 18,750 individuals (duplicated) benefited from the Highmark Foundation grants. The majority of individuals (9,697) were reached and served through participation in outreach events, including social media campaigns — 2,082 were screened, 4,495 were engaged in prevention and education programs, and 2,082 were linked to care.

HIV Prevention Challenges

The battle against HIV infection is becoming more difficult to overcome due to an increase in STDs, hepatitis C, and drug use in the United States. Cases of chlamydia, gonorrhea, and syphilis hit a record high in 2015.¹ Although the incidence of HIV infections⁴ and diagnoses are declining in the United States, the link between HIV infection and sexually transmitted infections is well established.

Hepatitis C is increasing among persons who inject drugs (PWID) due in part to the devastating opioid epidemic. These various modes of transmission create complex challenges to forming effective strategies to combat HIV. Further challenges include stigma, lack of knowledge of appropriate health care providers, and low levels of awareness and communication between providers and the public.

Figure 3
Reported Rate of STDs per 100,000:
Pennsylvania 2012 – 2016

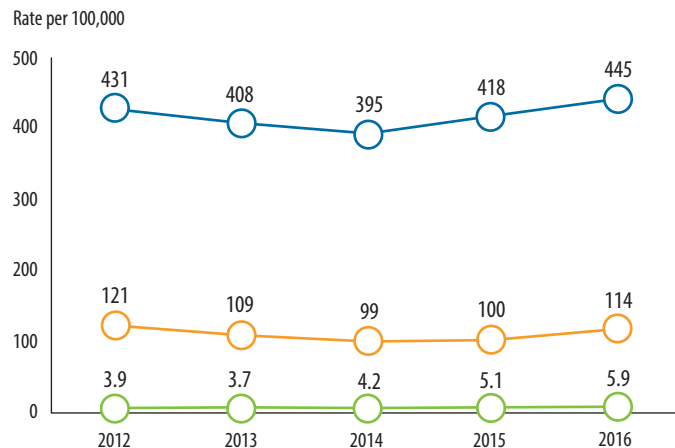


Figure 2
HIV/AIDS Organizations by Region

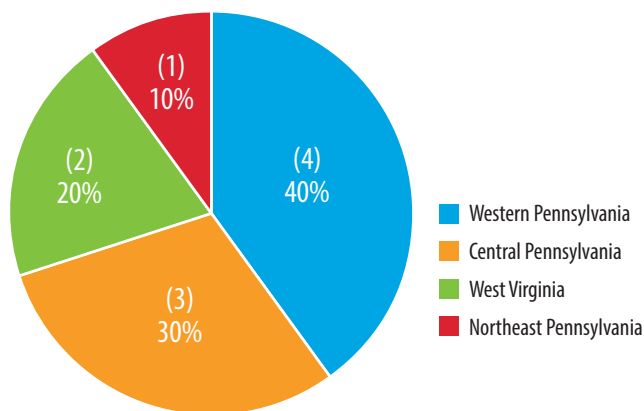
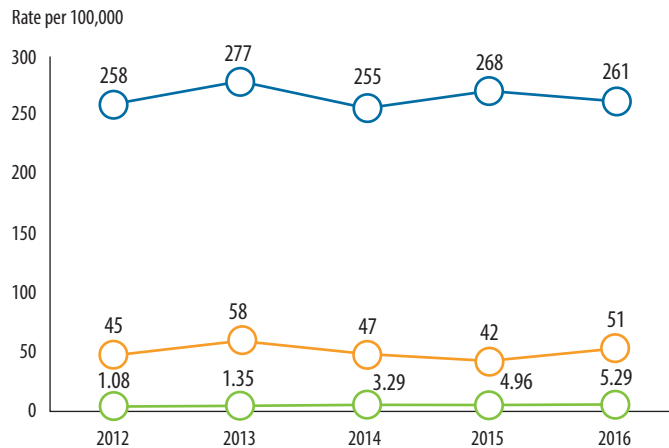


Figure 2 shows the number and percent of organizations according to geographic region. The majority of organizations awarded were located in western Pennsylvania.

Figure 4
Reported Rate of STDs per 100,000:
West Virginia 2012 – 2016



Figures 3 and **4** highlight the reported rates of chlamydia, gonorrhea, and syphilis for Pennsylvania and West Virginia from 2012 to 2016. A significant increase in all STDs can be seen from 2015 to 2016. This increase is consistent with the rise in STD rates also observed in the United States.

Figure 5
Reported Cases of Hepatitis C per 100,000:
Pennsylvania and West Virginia 2011 – 2015

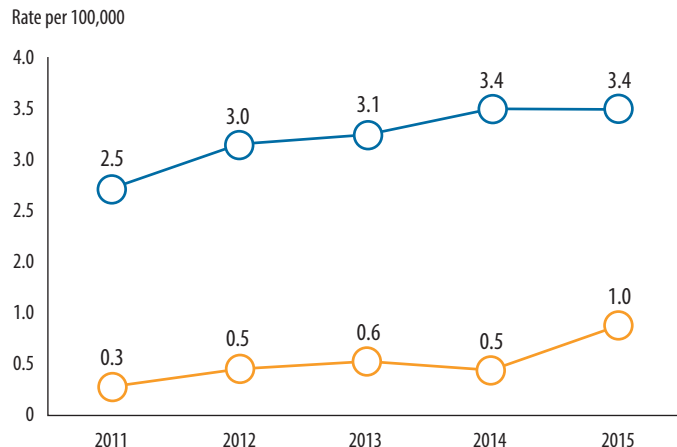


Figure 5 indicates a gradual increase in hepatitis C for Pennsylvania and West Virginia from 2011 to 2015. **Figure 6** shows a declining rate of HIV diagnoses in Pennsylvania and West Virginia. The significant decline observed in 2016 was similar to that reported overall for the United States. A contributing factor for the increasing rates could be contributed to the intensified use of opioids.

HIV Prevention and Treatment

As a result of advances in HIV treatment and care, people with HIV/AIDS are living much longer when compared to those over two decades ago. There is no cure for HIV/AIDS yet; however, successful prevention programs and treatments are slowing the rate of infection. Organizations that provide HIV/AIDS services can assume a crucial role in delivering comprehensive, integrated, evidence-based prevention strategies and harm reduction education. Current therapies recommended for people living with HIV/AIDS or people at risk of infection include: Pre-exposure prophylaxis (PrEP) that prevents HIV negative at-risk individuals from being infected with HIV; Antiretroviral therapy (ART) — a combination of three or more antiretroviral medicines — is much more effective than a single (monotherapy) to treat HIV; and Post-exposure prophylaxis (PEP) involves taking antiretroviral (ARV) medicines immediately after a possible exposure to prevent becoming infected with HIV.

What We Did

HIV/AIDS and STDs continue to be pervasive public health concerns. As a result, in 2016, the Foundation awarded one-year mini-grants totaling \$90,000 to 10 organizations to implement HIV/AIDS care and services in central Pennsylvania, western Pennsylvania and West Virginia. Its overall strategy included supporting effective, evidence-based programs with data driven outcomes that help reduce costs, minimize barriers, and get people into care earlier. Each grantee demonstrated how programs were used to help to reduce barriers for individuals and communities served.

Strategies demonstrated measurable outcomes and addressed population health in one of these areas as shown in **Figure 7**.

Figure 6
Rate of Reported Cases of HIV Diagnosed per 100,000:
Pennsylvania and West Virginia 2008 – 2016

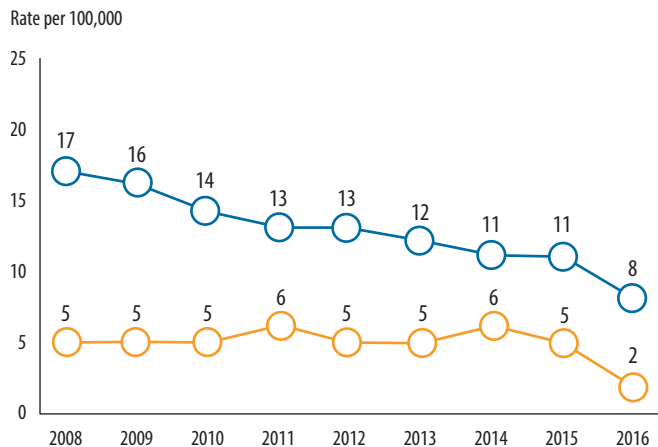


Figure 7
HIV/AIDS Organizations by Priority Area

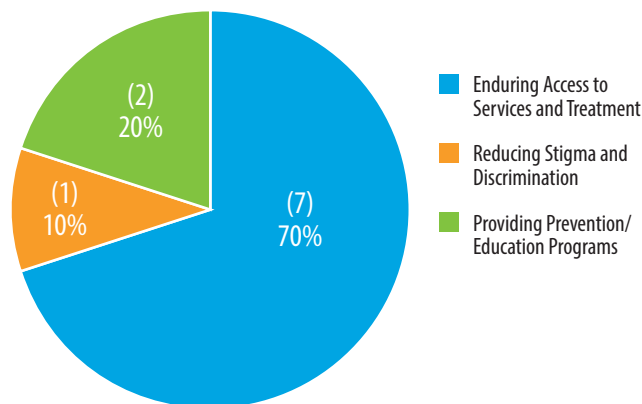


Figure 7 highlights the number of organizations by priority areas and strategies. Seven grantees (70%) focused on ensuring access to services and treatment while only one (10%) focused on reducing stigma and discrimination.

1. **Reducing Stigma and Discrimination** which has lessened over time, but remains significantly prevalent to create an important challenge
2. **Ensuring Access to Services and Treatment** to effectively link HIV-infected persons with recommended care and treatment
3. **Providing Prevention/Education Programs** to develop a more targeted approach to prevent the spread of HIV/AIDS and STDs

Why It Worked

Services provided by the organizations varied; however, several focused specifically on a single goal, while others provided services encompassing goals from all three priority areas such as:

- Identify and refer populations that most needed additional prevention support.
- Link patients from testing to care with integrated services.
- Improve access to community health programs, treatment, and services.
- Expand HIV and STD screening, testing, and counseling.

- Develop and implement evidence-based or innovative best practice strategies designed to change or improve community health systems.
- Report qualitative and quantitative outcomes.

The organizations collectively showed that a multidimensional approach was necessary to improve the quality of treatment, service, and education. These programs offered people with access to opportunities they normally would not have had. As a result, these types of services should continue to reduce the increase of HIV/STDs and Hepatitis C rates in this region.

Table 2
Engaging and Empowering Communities to Address HIV/AIDS and STDs

Organization	Grant Purpose
Ensuring Access to Services and Treatment	
AIDS Resource Alliance	Implementation of Anti-Retroviral Treatment and Access to Services (ARTAS) and hiring a linkage coordinator to support the organization's expansion
Caritas House	Accessible Rapid Testing (ART) to ensure high-quality quick HIV testing services
Co-County Wellness Services	"We're Doing It Berks" program to ensure access to HIV/STD services for Men who have Sex with Men (MSM) and the Latino/a population through social media campaigns
Community Human Services	Peer navigation to provide supportive services for LGBT youth of color through Project Silk (a CDC-funded demonstration project)
Milan Puskar Health Right	Harm reduction through the Light Project Harm Reduction program that provided access to hepatitis C testing for those at risk
Pittsburgh AIDS Task Force	Individuals at high risk of HIV infection were enrolled into PrEP services by linking newly diagnosed individuals with HIV to medical care
Planned Parenthood Keystone	Provision of no-cost HIV and STD tests to low-income patients.
Providing Prevention/Education Programs	
Allentown Health Bureau	Provide increased access to STD care and prevention, education, and screening of patients.
Central Outreach Resource and Referral Center	Support the Empowerment Through Education and Outreach program which provides HIV testing, outreach, and education to persons at risk of HIV/STD through mobile services
Reducing Stigma and Discrimination	
Macedonia Family and Community Enrichment Center	Implementation of HIV/AIDS case management and prevention programs to reduce stigma and discrimination using an HIV-positive individual as a peer navigator



Table 2 describes the programs supported by the grant. These programs successfully ensured access to care and treatment for affected populations. These small grants have allowed grantees to create models with potential replication, demonstrate new and sustainable ways to solve health issues, and illustrate the effectiveness of early intervention and prevention.



Challenges/Lessons Learned

- Many potential referral opportunities may be missed due to service providers not being aware of all HIV/AIDS organizations, especially those operating under the radar.
- The difficulty in maintaining and preserving clients' confidentiality could lead to unintended outcomes.
- Finding appropriate methods to collect program data for walk-in programs combined with limited staff or funding is always an issue.
- Social media has the ability to enhance engagement and to reach deeper into communities; however, staff training on effective use of social media remains a challenge.
- Clients' attitudes coupled with barriers faced make it difficult for organizations to provide timely treatment and/or referral services.
- Medicaid does not cover treatment for Hepatitis C if the person is a current injection drug user; therefore, no access to treatment is available for the uninsured. This issue has led some clients to choose not to be aware or to actively ignore their status regarding HIV/AIDS and STDs.
- Lack of knowledge in the population contributes to risky behavior. Consequently, there is a need for regular screening and sufficient funding to ensure those who need to be screened receive the service.
- The fear among PWID of being arrested, losing employment, or being forced into treatment is identified as possible barriers to screening and treatment.
- Long wait times for an appointment to see an infectious disease specialist are deterrents to screening and early treatment.
- No shows and attrition between screening appointments and first doctor appointment are also common among this population.
- Mobile unit services are an efficient way to reach people in communities.
- Educating staff on re-emerging infectious diseases is a necessity.
- Using peer navigators to implement an HIV prevention program could create roadblocks, because they are as vulnerable as the clients they work with as they face the same challenges, stresses, and barriers.
- Keeping clients in treatment for extended periods of time and making follow-up calls could be challenging and time consuming.
- Lack of funding was not listed as a reason for not continuing the programs.
- Although many individuals were reached through this funding, many more remain unaware of their HIV/AIDS, STDs, and Hepatitis C status and consequently still practice risky behaviors that make them vulnerable to infection. More funding will be needed to scale up ongoing efforts to combat the spread of HIV/AIDS and STDs in the region.

Sustainability of HIV/AIDS Program

Resources such as AIDS coalitions, the Centers for Disease Control and Prevention, the Ryan White HIV/AIDS Program, the Department of Health and Human Services, contracts, local foundations, and the 340B Drug Discount Program can assist with providing much-needed funding and assistance in sustaining programming. Individual donations and fundraising campaigns are also viable sources to help sustain programs for additional years.

“Thank you. Not only did I get checked for an STD, the doctor suggested I get tested for Lyme disease. Thanks to her, I am being treated for both.”

—PATIENT, ALLENTOWN HEALTH BUREAU

“In short, HIV/AIDS reduction in life chances is a public health problem that is not driven by the disease, but stigma and systemic oppression.”

—PROVIDER, COMMUNITY HEALTH SERVICES

Conclusion

Although the services varied throughout the organizations, each used the funding to reduce barriers, lessen the stigma, and ensure access to HIV/AIDS programs and services. Services provided through both programs were at no cost to participants, and most programs successfully achieved their goals. As a result of the programs, 18,585 individuals were reached through the efforts of the 10 HIV/AIDS organizations.

Successes achieved by the HIV/AIDS programs and services demonstrate that using a multifaceted approach, especially when integrated with social media, is effective in reaching vulnerable communities. The Foundation's interest in confronting HIV/AIDS and STDs and other risk factors has grown out of its commitment to supporting families and communities. The impactful work being done by HIV/AIDS organizations using mini grants has created an opportunity for HIV/AIDS organizations to seek new and bigger funding sources to sustain and eventually expand current efforts in combating the rise in HIV/AIDS and STD infections.

“Project Silk creates a safe space and non-traditional health setting.” A Project Silk member commented that the space is “a place where I can be myself and where I can give the world.”

“I think I keep coming back because, number one, I think it is the unity that everyone wants to come together and do something like this. Also, it is helping my community and for people who are coming up just like me and for people who have already came up still get to take advantage of something like this. Just to be part of this is its own reward.”

—PROJECT SILK MEMBER,
COMMUNITY HUMAN SERVICES

Next Steps

- Considering the ravaging event of the opioid epidemic, it is timely and necessary to provide adequate funding for HIV/AIDS organizations' current efforts to address the rise of STDs and Hepatitis C in the region.
- Partnerships that help cut costs, increasing linkages to care and referrals aimed at improving community health.
- Investing in outreach events and prevention/education campaigns for HIV/STDs and Hepatitis C in central and western Pennsylvania and West Virginia is crucial.
- Technical assistance support is needed for data collection. Proper data collection and analysis will reveal the scope of the problem and potential effective approaches to address the scope.
- Social media is a very efficient and cost-effective way to reach many people, especially the “hard to reach” population.
- Many of the organizations providing HIV/AIDS and STD services do not have the resources needed to develop a social media platform within their organizations, nor the ability to afford hiring experts. Funding for staff training and development of social media platforms is crucial to reaching more people.
- Re-examine guidelines regarding drug use and Medicare and Medicaid coverage.
- Improve collaboration and coordination with related service providers to widen access to additional support programs. Identify individuals at risk for infection, educate them about the need for appropriate care, and refer them to services.

“It means so much to have someone that I can talk to about my life as a gay man. I feel like you truly care and wanting me to be safe and healthy means so much. I absolutely love getting my meds in the mail every month. The pharmacy is super nice and helpful.”

—CLIENT, PITTSBURGH AIDS TASK FORCE



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3. MMWR - Increase in hepatitis C virus infection related to injection drug use among person aged ≤30 years – Kentucky, Tennessee, Virginia, and West Virginia 2006 – 2012. May, 2015/64 (17); 453-458.
4. Centers for Disease Control and Prevention. HIV Surveillance Report, 2015; vol. 27.

About the Highmark Foundation

The Highmark Foundation is a private, charitable organization that supports initiatives and programs aimed at improving community health. The Foundation's mission is to improve the health, well-being, and quality of life for individuals who reside in the communities served by Highmark Inc., and its subsidiaries and affiliates. We fulfill our mission by awarding high-impact grants to charitable organizations that implement evidence-based programs. Central to the Foundation's mission is identifying and continuously re-evaluating our region's prevailing health needs. By doing so, the Foundation remains at the forefront of those needs, well equipped to pinpoint issues that most urgently need support. For more information, visit

www.highmarkfoundation.org

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